Newborn Screening Dried Bloodspot Collection Form Educational Webinar

March 9, 2017

Ashley Comer, Joyal Meyer and Katie Bentz

Presenters

- Ashley Comer, Newborn Screening Quality Improvement Coordinator, State Hygienic Laboratory, Iowa
- Joyal Meyer, RN, MSN, ND Newborn Screening Program Director
- Katie Bentz, RN, BSN, ND Newborn Screening Program Nurse Consultant

NORTH DAKOTA DEPARTMENT of HEALTH

North Dakota Newborn Screening Program

STATE HYGIENIC LABORATORY
Iowa's Environmental and Public Health Laboratory
EST. 1904
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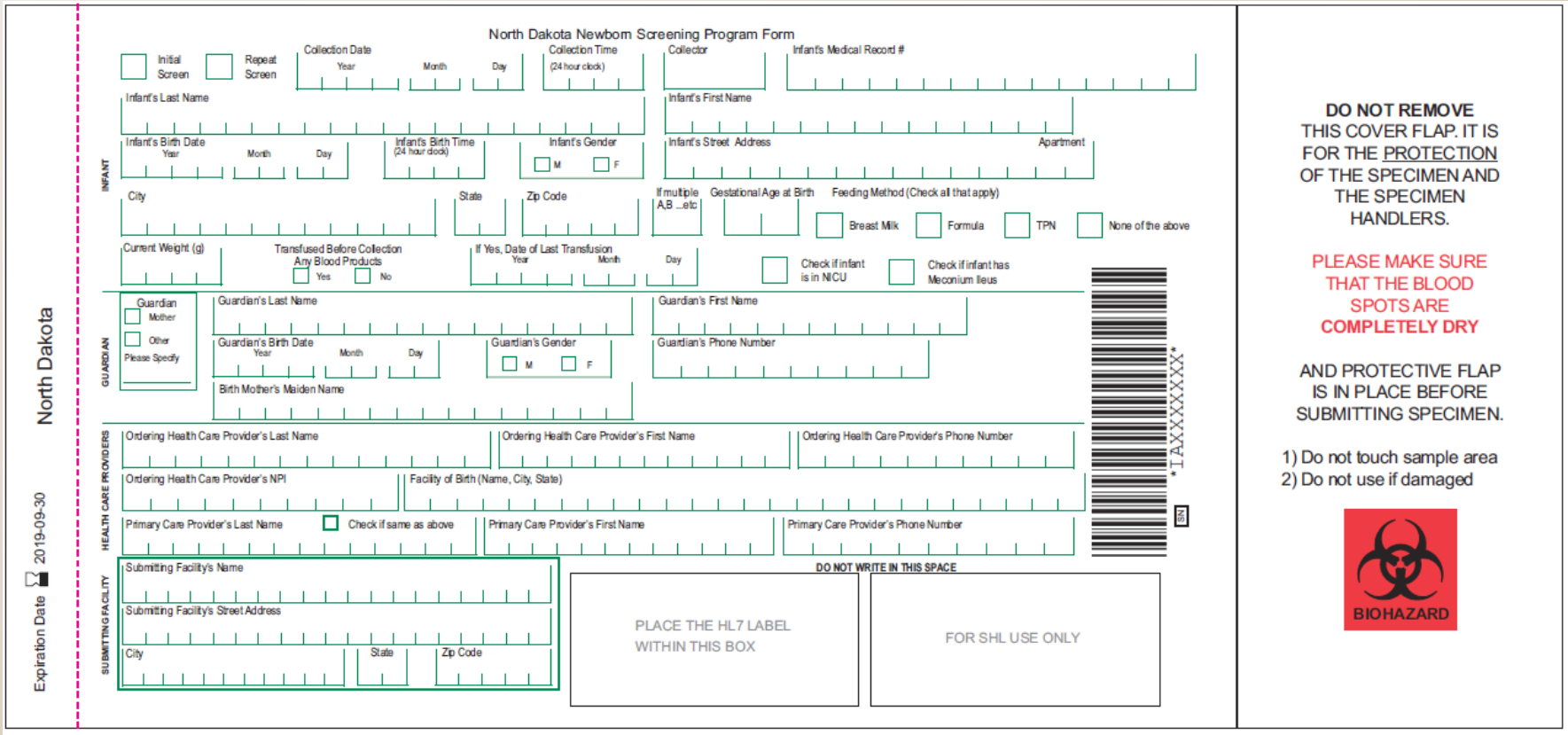
Redesigned Card



- Overall appearance similar to current card – color updated to green.
- Additional fields added and arrangement of fields altered.

Educational Material

- An educational fact sheet will be sent with the new forms.
- Can be used for orientation of new staff or refresher for current staff

It’s not just a form… It’s a baby

- Filling out the newborn screening form…
  - ✓ Accurately
  - ✓ Completely
  - ✓ Legibly

  Could be a matter of life and death

- <u>Inaccurate or missing information may adversely affect screening results and/or the ability to quickly contact the infant’s care provider in the event of an abnormal screening result.</u>

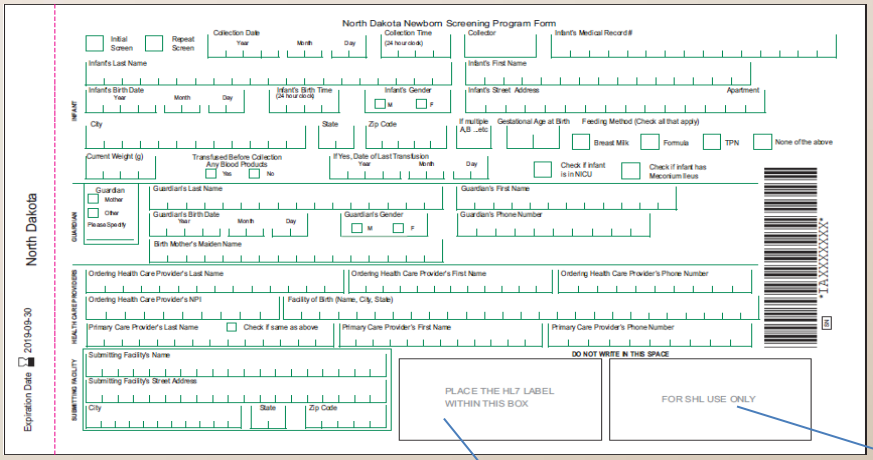
- *Any delay may put the child’s health at risk*.

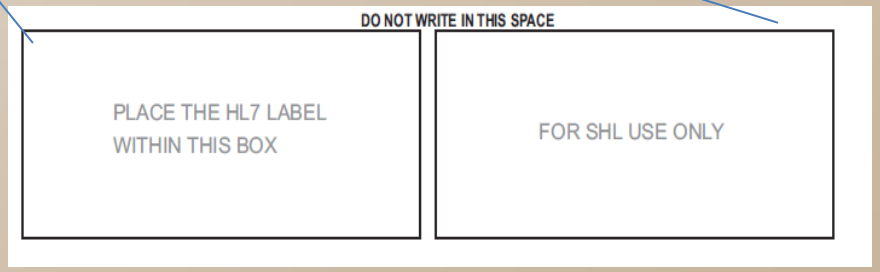
- The specimen submitter is legally responsible for the accuracy and completeness of the information on the newborn screening card.

Remember to remove 2nd ply for facility’s records.

Health Level 7 (HL7)

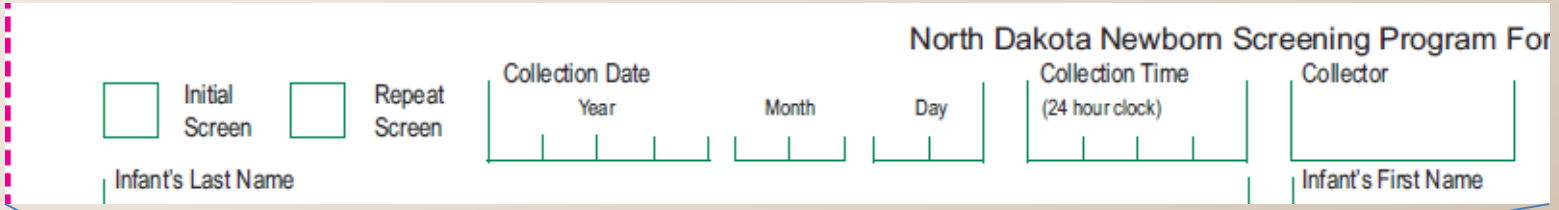
- ND Facilities do not use HL7 at this time.

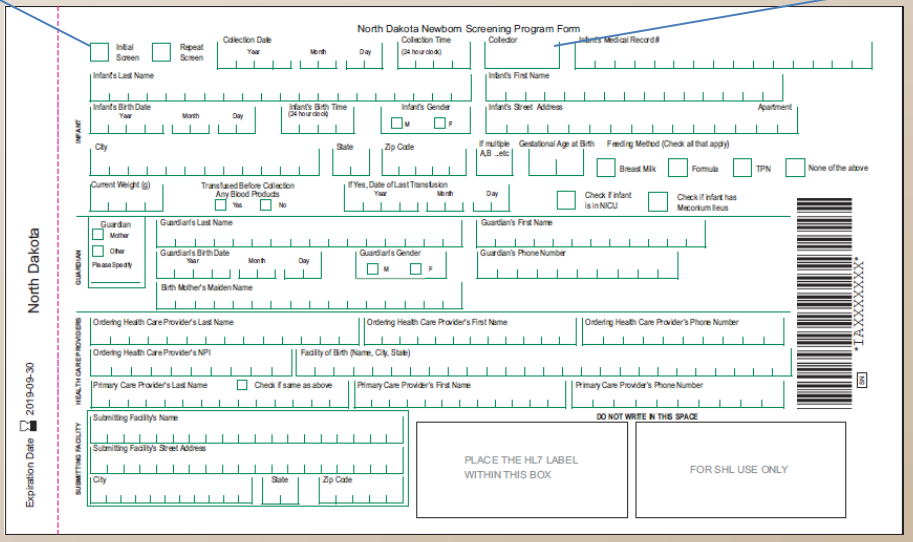




- Please do not write in the box “FOR SHL USE ONLY”

Sample Information





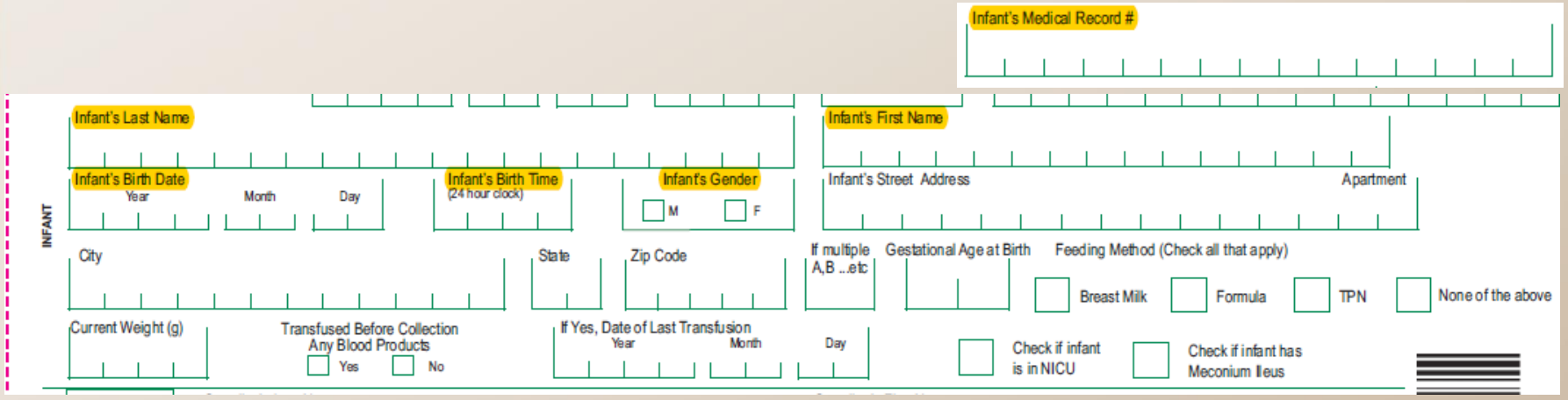
Changes

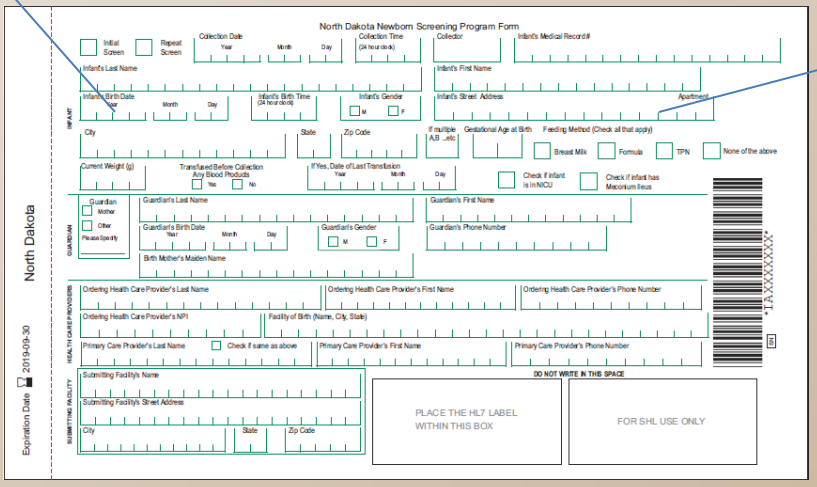
- Collection information moved to top of form
- Collection date format YYYY MM DD

Initial Screen= 1st submission

Repeat Screen= Any subsequent submissions received after the initial screen, even if 1st submission was rejected due to poor quality, early collection, etc.

Infant Information

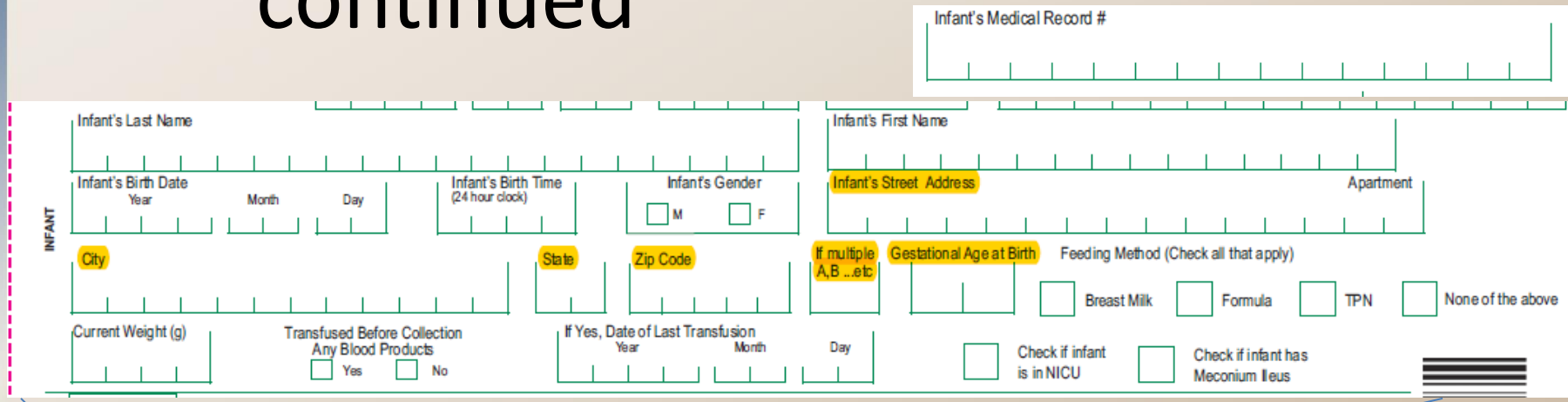


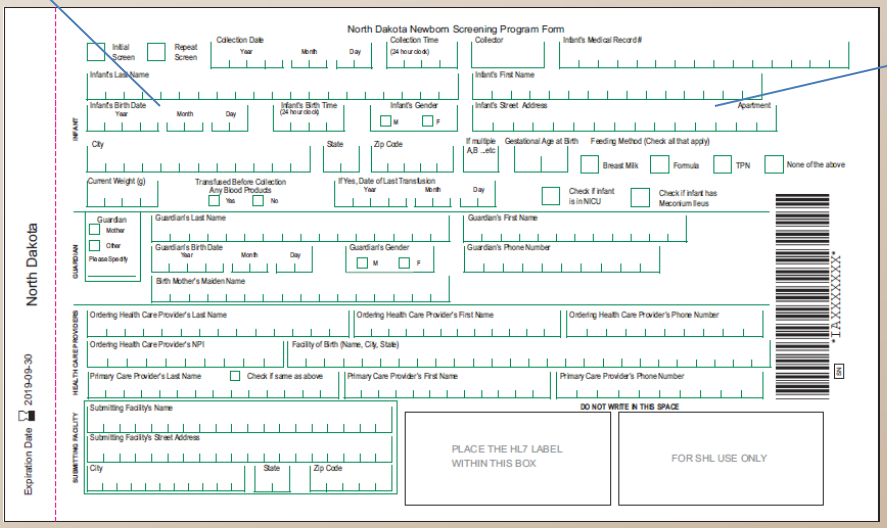


Changes

- Current card uses the term “chart number” and new form uses MRN
- DOB format YYYY/MM/DD

Infant Information continued

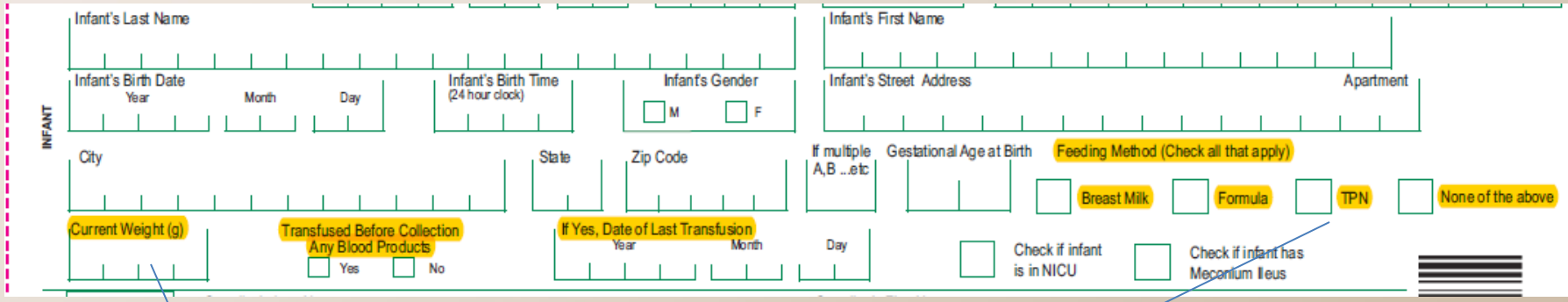


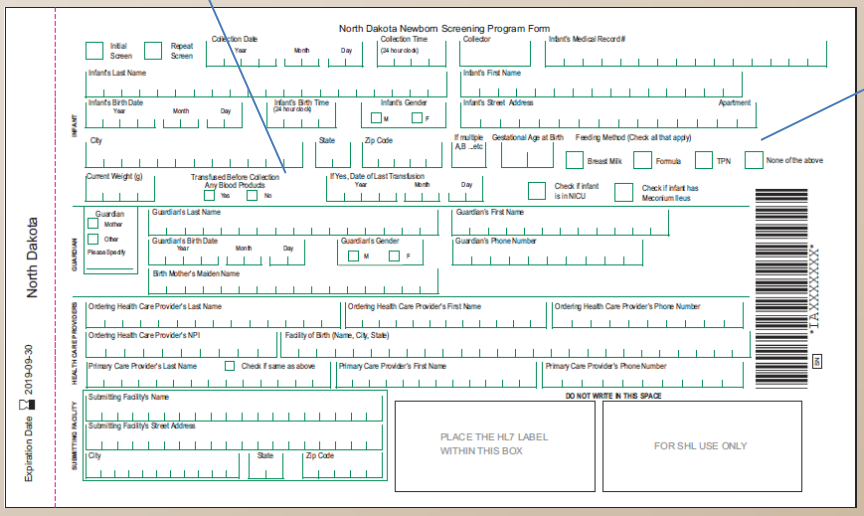


Changes

- Infant's street address
- List multiple births using A,B,C etc
  Only applicable for this pregnancy

Infant Information continued

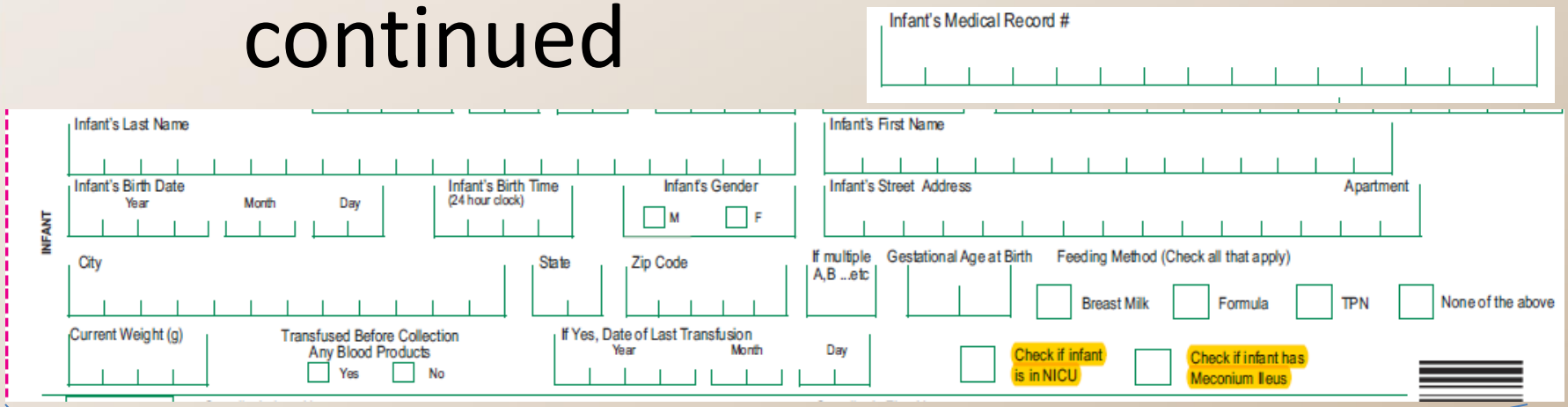


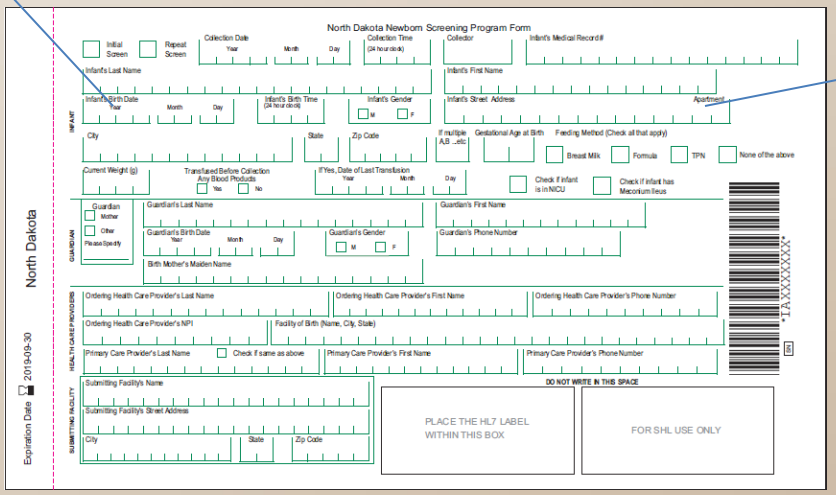


Changes

- Feeding method options changed
- Transfusion date format YYYY MM DD

Infant Information continued

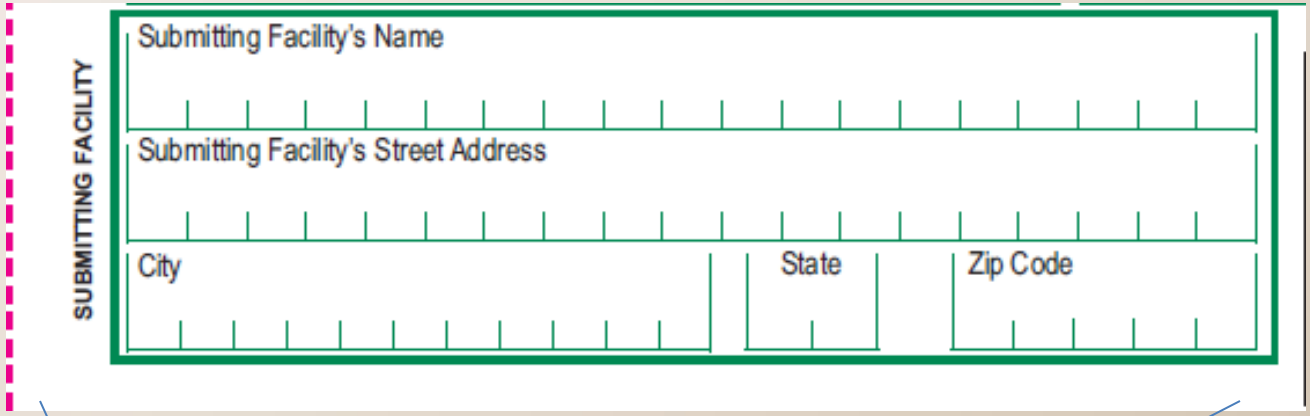


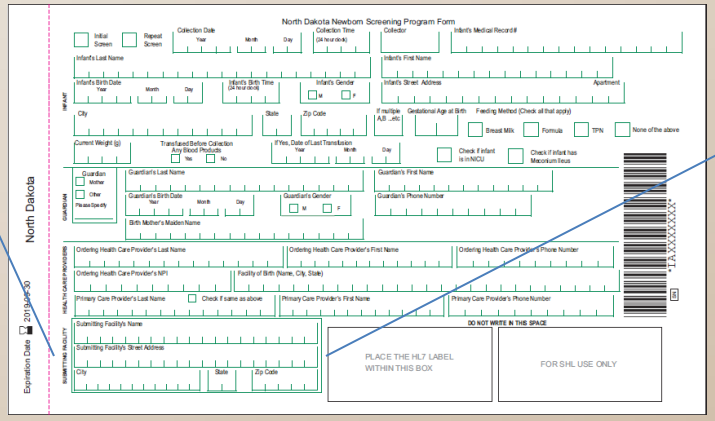


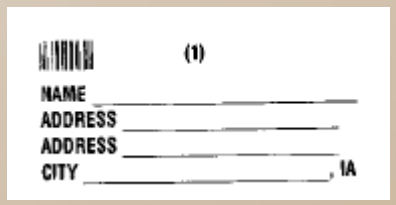
Changes

- NICU box moved
- Meconium Ileus box added

Submitter Information







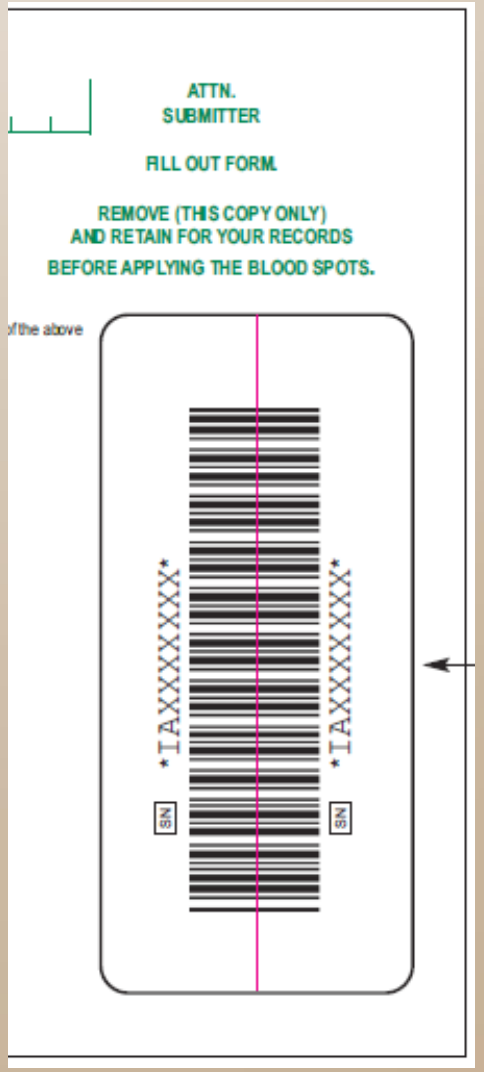
Changes

- Facility ID's are changing in our new LIMS system so this field was removed.
- Pre-printed label with submitter name and address will be provided with forms instead to accurately identify submitter.

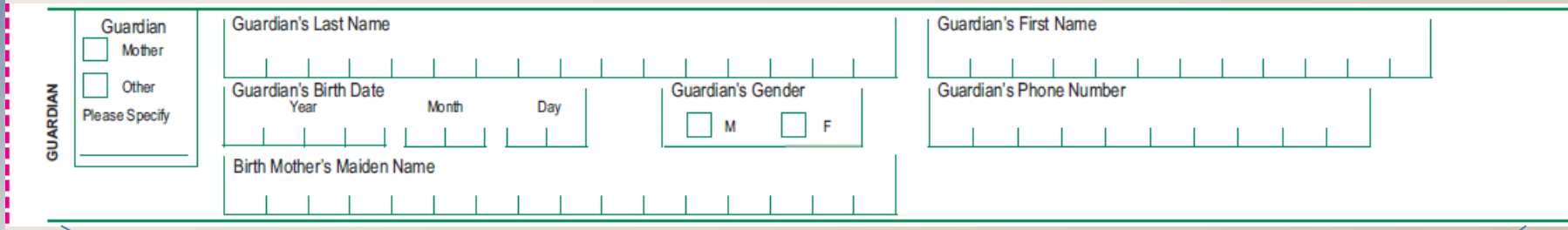
Barcode Stickers

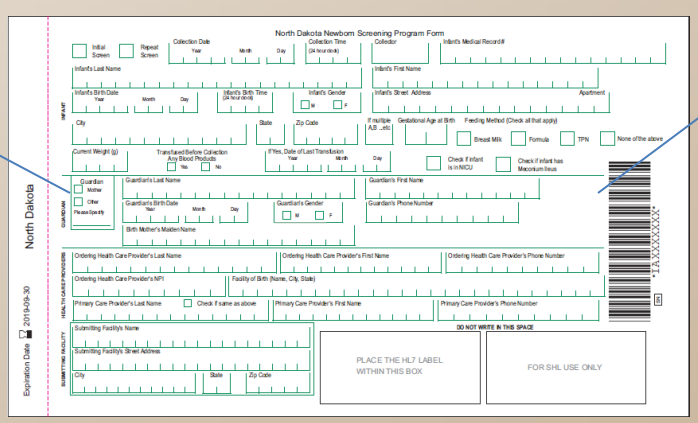
Changes

- A sticker was added to the portion of the form that is retained by the submitting provider.
  - One half of the sticker is to be placed on the birth certificate worksheet to help ensure the proper IA number is entered.
  - The other half of the sticker should remain on the card for your facilities records.



Guardian Information

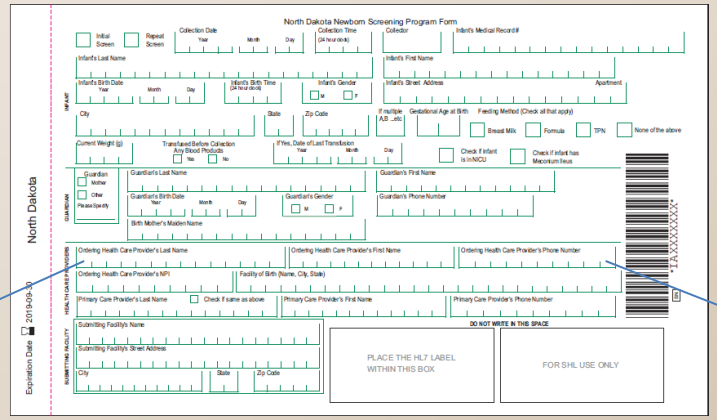




<u>Changes</u>

- Changed section from Mother to Guardian.
  - **If biological mother is the legal guardian, please provide her information.**
- Added Box to determine relation to infant: Mother or Other Guardian.
- Added a section to capture Birth Mother's Maiden Name for birth match purposes.

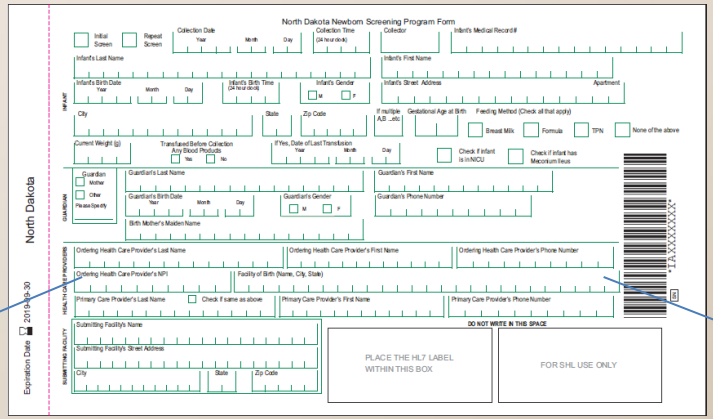
Health Care Provider Information

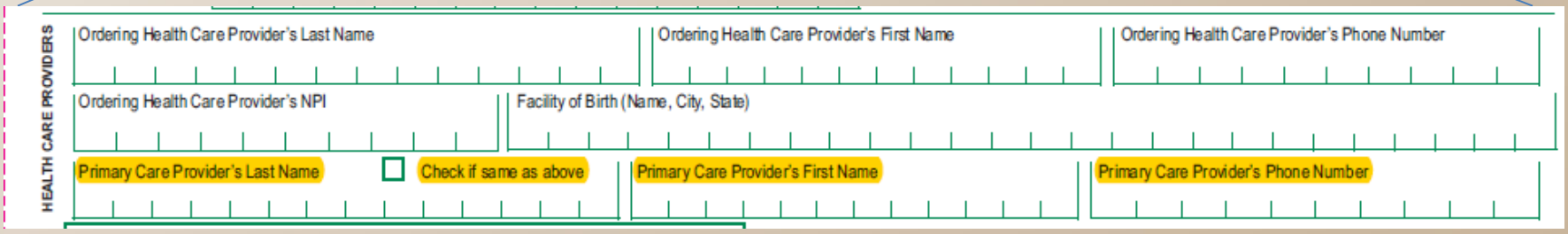


Changes

- Fields for both Ordering Health Care Provider AND Primary Care Provider
- Ordering Health Care Provider Number (NPI)
  https://npiregistry.cms.hhs.gov/

Health Care Provider Information

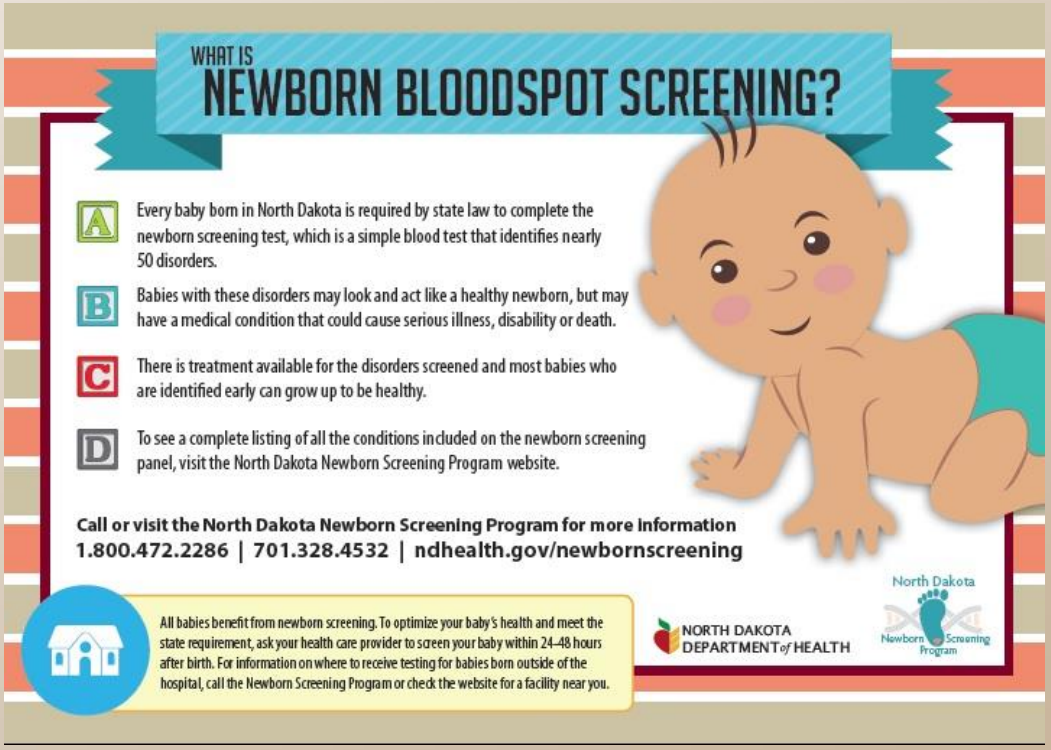




The NBS program requests PCP information if known at time of collection.
During education to parents about newborn screening or before the sample is collected, please ask the guardian who or where they plan on taking the newborn to for their first well check visit.

Education

- Before a newborn screen is obtained, the parent or guardian should be educated on:
  - The type of specimen
  - How it is obtained
  - Disorders screened for
  - Consequences of treatment and non-treatment
  - Retention, use, and disposal of residual specimens

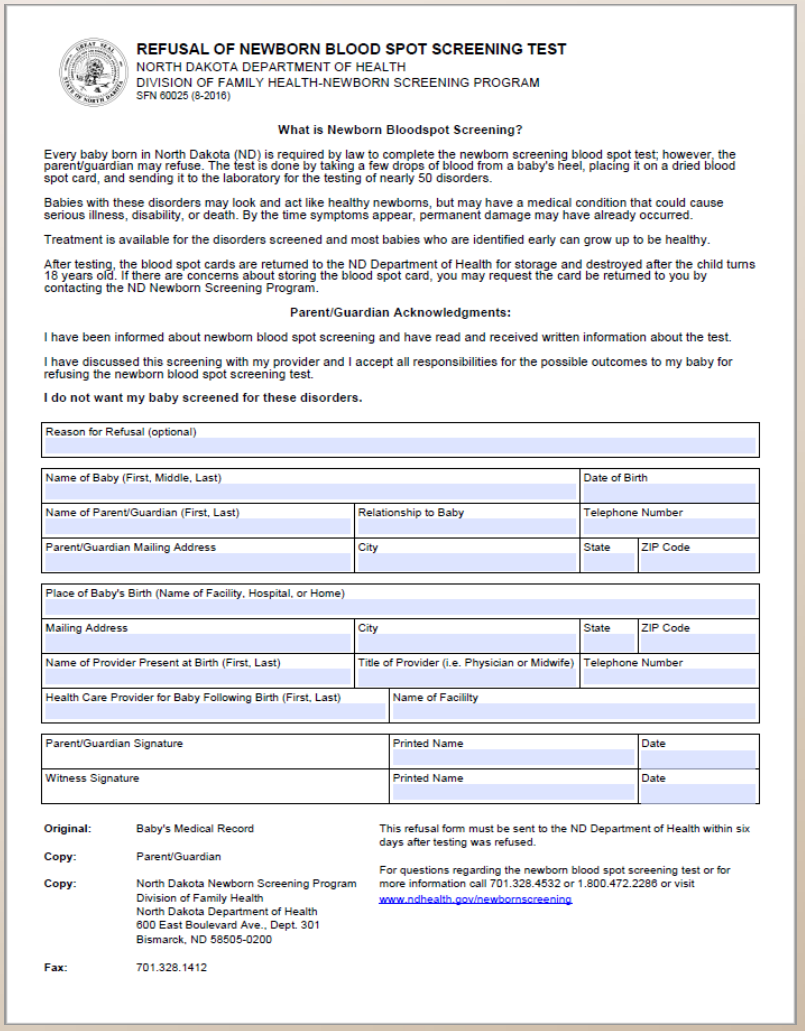


ND Newborn Screening Program brochures are available at https://nbs.health.nd.gov/

Newborn screening educational resources are available to assist in education.

One Foot at a Time Video http://savebabies.org/video.html

Refusals



REFUSAL OF NEWBORN BLOOD SPOT SCREENING TEST
NORTH DAKOTA DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH-NEWBORN SCREENING PROGRAM
SFN 60025 (8-2016)

What is Newborn Bloodspot Screening?

Every baby born in North Dakota (ND) is required by law to complete the newborn screening blood spot test; however, the parent/guardian may refuse. The test is done by taking a few drops of blood from a baby's heel, placing it on a dried blood spot card, and sending it to the laboratory for the testing of nearly 50 disorders.

Babies with these disorders may look and act like healthy newborns, but may have a medical condition that could cause serious illness, disability, or death. By the time symptoms appear, permanent damage may have already occurred.

Treatment is available for the disorders screened and most babies who are identified early can grow up to be healthy.

After testing, the blood spot cards are returned to the ND Department of Health for storage and destroyed after the child turns 18 years old. If there are concerns about storing the blood spot card, you may request the card be returned to you by contacting the ND Newborn Screening Program.

Parent/Guardian Acknowledgments:

I have been informed about newborn blood spot screening and have read and received written information about the test.

I have discussed this screening with my provider and I accept all responsibilities for the possible outcomes to my baby for refusing the newborn blood spot screening test.

I do not want my baby screened for these disorders.

Reason for Refusal (optional)			
Name of Baby (First, Middle, Last)			Date of Birth
Name of Parent/Guardian (First, Last)	Relationship to Baby		Telephone Number
Parent/Guardian Mailing Address	City	State	ZIP Code
Place of Baby's Birth (Name of Facility, Hospital, or Home)			
Mailing Address	City	State	ZIP Code
Name of Provider Present at Birth (First, Last)	Title of Provider (i.e. Physician or Midwife)		Telephone Number
Health Care Provider for Baby Following Birth (First, Last)	Name of Facility		
Parent/Guardian Signature	Printed Name		Date
Witness Signature	Printed Name		Date

Original: Baby's Medical Record

Copy: Parent/Guardian

Copy: North Dakota Newborn Screening Program
Division of Family Health
North Dakota Department of Health
600 East Boulevard Ave., Dept. 301
Bismarck, ND 58505-0200

Fax: 701.328.1412

This refusal form must be sent to the ND Department of Health within six days after testing was refused.

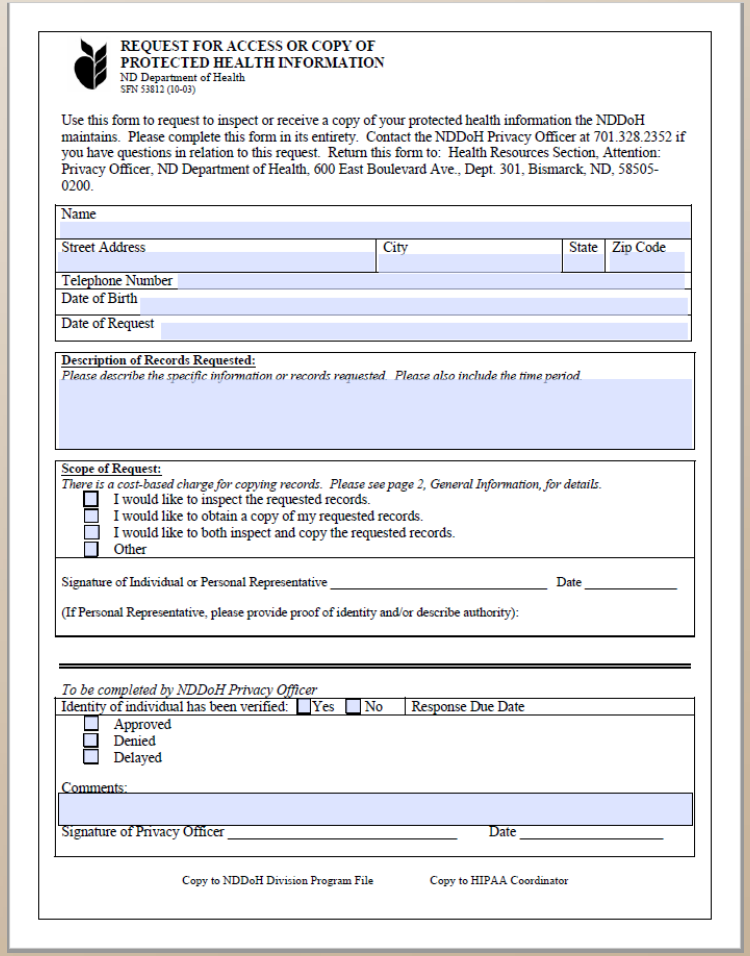
For questions regarding the newborn blood spot screening test or for more information call 701.328.4532 or 1.800.472.2286 or visit www.ndhealth.gov/newbornscreening

- Parents/Guardians are allowed to refuse the newborn screen under ND law.
- Prior to refusal, education on the testing should be provided.
- Families are required to complete the “Refusal of Newborn Blood Spot Screening Test” form.
  - Once the testing is refused, the form should be completed and returned to the program within 6 days.

https://nbs.health.nd.gov/materials-resources/files/brochure/refusalform/

Return of Specimen

- Families may request to have the specimen returned to them as an alternative to refusing testing.
- A Request for Access of PHI must be completed and returned to the program to have the specimen returned.
  - Providers can place a notification with the specimen when sending it to the lab to help flag the form to expedite the process of returning it.



REQUEST FOR ACCESS OR COPY OF PROTECTED HEALTH INFORMATION
ND Department of Health
SFN 53812 (10-03)

Use this form to request to inspect or receive a copy of your protected health information the NDDoH maintains. Please complete this form in its entirety. Contact the NDDoH Privacy Officer at 701.328.2352 if you have questions in relation to this request. Return this form to: Health Resources Section, Attention: Privacy Officer, ND Department of Health, 600 East Boulevard Ave., Dept. 301, Bismarck, ND, 58505-0200.

Name

Street Address | City | State | Zip Code

Telephone Number

Date of Birth

Date of Request

Description of Records Requested:
Please describe the specific information or records requested. Please also include the time period.

Scope of Request:
There is a cost-based charge for copying records. Please see page 2, General Information, for details.
- ☐ I would like to inspect the requested records.
- ☐ I would like to obtain a copy of my requested records.
- ☐ I would like to both inspect and copy the requested records.
- ☐ Other

Signature of Individual or Personal Representative _____ Date _____

(If Personal Representative, please provide proof of identity and/or describe authority):

To be completed by NDDoH Privacy Officer

Identity of individual has been verified: ☐ Yes ☐ No | Response Due Date

- ☐ Approved
- ☐ Denied
- ☐ Delayed

Comments:

Signature of Privacy Officer _____ Date _____

Copy to NDDoH Division Program File Copy to HIPAA Coordinator

https://nbs.health.nd.gov/image/cache/Request_for_Access_PHI.pdf

Coming soon…

Monthly Webinar Series from the ND Newborn Screening Program

Topics include:

- NBS Website/Resources
- Facility Reports/Navigate through the NBS Database
- Courier Services
- Prenatal Education for NBS
- NBS Stories from families
- What comes after NBS for infants with disorders
- History of Disorders
- Follow-up

Be on the lookout for info on the April webinar

We want to hear from you! If you'd like to suggest a topic email us at nbs@nd.gov

Contact Information

- Iowa State Hygienic Laboratory – 515.725.1630 for questions regarding:
  - Data entry or corrections
  - Order dried blood spot collection forms
  - Collection supplies

- Short-term Follow-up Nurses – 319.384.5097 or toll free 1.866.890.5965 for questions regarding:
  - Follow up testing on abnormal newborn screenings
  - Letters sent to providers from follow-up

- ND Newborn Screening Program – 701.328.4532 or 1.800.472.2286 for questions regarding:
  - Resources for newborn screening
  - Century Code/Legislation/
  - Refusals

Questions